



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
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Dover, Delaware 19901
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The Honorable John Carney
Governor

John McNeal
SCPD Director

BRAIN INJURY COMMITTEE
June 4, 2018 – 2:00 PM
Smyrna Rest Area Conference Room, Smyrna, DE

MINIMUM QUORUM OF 11 MET

PRESENT: Ann **Phillips**, Chair, Parent of a survivor; Sharon **Lyons**, BIAD, Co-Chair; Christina **Applegate**, Bayhealth Neurosurgery; Andrew **Burdan**, Brain Injury Advocate/Support Group; Thomas **Cairo**, Bayhealth Neurosurgery; Katie **Freeman**, DSCYF, DPBHS, Psychologist (for Robert Dunleavy LCSW); Kristin **Harvey**, DDC (for Steve Yeatman); Dr. Charles **Jin**, (DSAMH); (for Elizabeth Romero, Director); Dale **Matusevich**, DOE, ECE, Education Associate, Transition Services (for Mary Ann Mieczkowski); Dr. Ron **Sarg**, DCVA/MOAA; DLP; Jamila **Waigwa**, DHSS/DSAAPD; and Dee **Rivard**, SCPD.

TELECONFERENCE PARTICIPANTS (does not count toward quorum): **Michelle Hood**, St. Francis LIFE;

ABSENT: Linda **Brittingham**, Christiana Care Health System (CCHS); Sybil **Brown**, GACEC (for Wendy Strauss, Chair); Tammy **Clifton**, DOL, DVR, VR Counselor I (for Andrea Guest, Director); Susan **Cowdery**, BCBS, Highmark Health Options; Vanessa **Deloach**, DHSS/DDDS, Assistant Director (for Marie Nonnemacher); Debbie **Dunlap**, Parent of a survivor/Advocate; Dr. Gerald **Gallucci**, Program Director, DHSS/DSAMH (for Elizabeth Romero, Director); Mary **Iampietro**, A. I. DuPont Children's Hospital; Karen **McGloughlin**, DPH, (for Dr. Karyl Rattay, Director); John **McNeal**, SCPD Director and survivor; Nancy **Ranalli**, Easterseals, Director of Community Outreach; Laura **Waterland**, Esquire, Community Legal Aid Society, Inc.; Clarence **Watson**, DHSS, Medical Director (for Elizabeth Romero, Director);

GUESTS

Erin Goldner, Hope Street DE;

CALL TO ORDER

Chair Anne Phillips called the meeting to order at 2:09 p.m., asking those around the table to introduce themselves stating the organization that they represent. The list of voting members in attendance is available at the top of these minutes. Tom Cairo introduced Christina Applegate as the Neurosurgery Nurse Navigator who is replacing Donna Dixon on the Committee for regular attendance as a representative for Bayhealth Kent General Hospital.

ADDITIONS/DELETIONS TO THE AGENDA

Anne inquired if there were any additions Hearing none, she announced that the membership review portion of the agenda was being moved to the first item of business.

APPROVAL OF PREVIOUS MEETING'S MINUTES

Ann asked if everyone was able to review the minutes of the April meeting since we did not have a quorum for the May meeting. She called for any additions, deletions, or changes. Hearing none, she inquired if a discussion of the minutes was requested by any member. With no member needing a discussion, Anne asked for a motion to approve the April meeting minutes. Tom Cairo made a motion to approve the minutes as prepared that was seconded by Sharon Lyons and unanimously approved by the voting members in attendance.

MEMBERSHIP REVIEW

- Anne Phillips, Chair began a line by line committee review of membership attendance and representation for each represented organization listed on the membership spreadsheet.

Legislatively Mandated Members

- **Director of Division of Public Health** –Designee attending
- **Director of the Division of Developmental Disabilities** – Designee attending
- **Director of the Division of Substance Abuse & Mental Health** – Representation attending
- **Director of Division of Services for Aging and Adults with Physical Disabilities** – Designee attending
- **Director of Division of Prevention and Behavioral Health Services;** Designee attending
- **Director of the Division of Vocational Rehabilitation** – Sending letter to obtain regular attendance due to no attendance since 12/4/17
- **Director Department of Education, DECR/Special Education, Exceptional Children** – Designee attending
- **Chair of Governor's Advisory Council For Exceptional Citizens** – Designee attending;
- **Representative of the State Chapter of the Brain Injury Association of America (BIA of DE)** – Representative attending
- **Representative of the "protection and advocacy agency" defined in § 1102 of Title 16 [Community Legal Aid Society, Inc.]** Representative participating by phone/Need in-person attendance

Minimum of 3 survivors of brain injury or family members of such individuals –

Removed 2 for non-attendance. Need to replace with 2 new members! Current attendees:

- Debbie and/or Jim Dunlap -- Attending
- Ann Phillips -- Attending

Representatives of prevention, planning, veterans and service delivery organizations appointed by the Council;

- **Sussex Brain Injury Support Group** – Representative attending
- **Delaware Commission of Veterans Affairs** – Representative attending

- **Veterans Affairs Hospital** Polytrauma & TBI Program – Removed for non-attendance. Col. Ron Sarg is contacting to see if they wish to provide regular representation.
- **Easterseals Delaware & Maryland Eastern Shore** – Representative attending
- **A. I. DuPont Hospital for Children** – Representative calling-in/Need in-person attendance. Sharon Lyons is contacting to see if they wish to provide regular in person representation.
- **Christiana Care Health System**, Polytrauma & TBI Program – Representative calling-in /Need in-person attendance. Notified existing representative of requirement for in-person attendance.
- **The SAFE Program of People's Place** – Removed due to non-attendance.
- **Saint Francis LIFE** – Regularly participates by phone /Need in-person attendance. Notified existing representative of requirement for in-person attendance.
- **Peachtree Acres** – Removed for non-attendance since change of ownership
- **Latin American Committee Council** – Removed for non-attendance
- **Hispanic Council** – Removed for non-attendance
- **Child Development Watch Program** – Removed for non-attendance. Ann Phillips contact to see if they wish to remain a member and will provide in-person representation regularly.
- **Beebe Health Care** – Removed due to non-attendance since 02/01/16
- **Point of Hope, Inc.** – Removed due to non-attendance.
- **AmeriHealth** -- Removed due to non-attendance.
- **Highmark Health Options** – Removed due to non-attendance.
- **Bayhealth Kent General Hospital** Neurosurgery – Representative attending.
- **DHSS/Office of Telehealth Planning & Development Medicine** – Representative resigned due to lack of staffing to permit attendance.

****NOTE**** All agencies noted as being removed for non-attendance are being contacted by a Committee member or SCPD staff to advise of the requirement for in-person attendance and to inquire if they wish to designate a representative who will regularly attend meetings in person.

*****NOTE***** Vice-Chair Sharon Lyons will contact Health South Rehabilitation Hospital on behalf of the Brain Injury Committee to invite them to designate a representative to regularly attend these meetings in-person.

OLD BUSINESS

- Follow-up Items
DHIN

Tom Cairo provided an overview of DHIN status including Katie Freeman's TBI Information

- Tom Cairo needs to understand if we are still moving forward with setting conversations up with DHIN to obtain a list of individuals within the state with TBIs. He stated that we have to decide on a list of diagnosis codes to request. Does the committee want to include people with Acquired Brain Injuries (ABIs), request only Traumatic Brain Injuries (TBIs) which include concussions, or define exactly what we

- want to request because it gets very specific? Tom advised that the information that Katie shared with everyone previously also went over stratification.
- Tom requested that everyone send him a wish list of what we would like the Committee to ask of DHIN. If you were to see a report, what would you like included as a part of that report. Also include secondary diagnosis. Send Tom a quick email at Thomas.Cairo@bayhealth.org.
 - Tom inquired if we want to include stroke, and anoxia. He has not included it as of yet. ICD-10 codes are very specific. What kind of data does the Committee want to see by age, race, and gender? Do you want to include demographic information? How is the Committee planning to use this information? Where were the brain injury patients discharged to?
 - Tom advised that the DHIN network does not include all hospitals, only those that participate in reporting to DHIN. The only thing that DHIN receives is what participating hospitals send to them. He warned members that it is possible to have a duplicated person if they are admitted to different hospitals. Most hospitals do not send much information to DHIN and the information received depends on identifiers that the Committee will not know. What can we get? What can't we get? Tom recommended going to DHIN with the optimal. Any data is better than no data.
 - The Committee is looking at things from the perspective of individuals who review grants such as whether or not the patient lives in the State of Delaware, the patient's age, race, income bracket, and whether or not brain injuries are increasing in trend or decreasing. If we are able to obtain the patient's income bracket that would be helpful.
 - If we request to have ABIs included, the numbers are going to be skewed toward the geriatric population. The same is true with the strokes; however, if we see that injuries are trending for a specific ethnic group or age group it would allow the state to do targeted care.
 - The Committee would like to know how the brain injury occurred; although, obtaining information on what led to the injury is going to be a big ask. We can try to look at some of that data from the hospital systems themselves. A suggestion to approach the requests for brain injury information from a perspective of "Help us help you" may encourage better sharing of information if the hospitals can see what is in it for them. Hospital information is historically about insurance and getting paid. What about public health data?
 - Tom is going to suggest a deadline of when he would like to see everyone's wish list. After he receives all of the wish lists, he will then schedule a meeting with DHIN to see if he can obtain some updated information.
 - What is the time frame of the data that the Committee wants to see? Tom told members that DHIN data is up to date and that there is no lag time. The Committee agreed that we would like to see 5 years of data. We should be looking at 2017 - 2018 YTD to start and then we can go back further at a later date. First let's see what data they can provide us including the number of TBIs, then breakdown by age, gender, and race and then geo-location by zip-code or school district. The income bracket will be an

interesting ask and the only way that we will get that is if DHIN is linked to something else like the State Tax database.

- Chair Ann Phillips advised that she received information from Kids Count by income and how many applied for TANF and Food Stamps, etc.
- Tom believes that we are going to get some basic information from DHIN and then the Committee will have to go to some of the bigger players within the state to try to obtain the other information. DHIN has some newer programs that are coming as they seem to be expanding. Going forward after our initial request, we can find out what they can provide and then the Committee could invite Medicaid or whomever has the data to fill some of the gaps in order to flesh out the details.
- Please get your information to Tom within 2 weeks by end of day on 6/15. Start with TBIs and then expand at a later date to ABIs. Unfortunately the hospitals and doctors like to use NOS which means “Not Otherwise Specified” to refer to the ICD-10 code and then never go back and change it.
- In response to a question as to whether or not A.I. DuPont Children’s Hospital gives data to DHIN; Tom responded that they do. Sharon Lyons will email Maura to inquire about TBI data.
- The Committee requested that Dee issue an invitation to Wayne Smith, President of the Delaware Healthcare Association asking him to let her know if he would be interested and willing to attend the BIC meetings. He may also be able to respond on behalf of Delaware Hospitals as to an inquiry for DHIN participation.
- Since Tom raised the question of whether or not the Committee is planning to meet over the summer, a majority of committee members responded that historically the Committee has taken a break over the summer due to vacations interfering with quorum. Following a discussion, the committee members present decided to cancel the July and August meetings resuming the BIC meeting on Monday, September 10.
- Dee reminded everyone that John was planning to task Karen McLaughlin with finding out what TBI information by year that she can obtain for the committee from Public Health.

Obtain name of volunteer from Committee to take a more active role with DHIN.

- Andrew Burdan volunteered to assume a more active role working with Tom Cairo on the DHIN project.

NEW BUSINESS

- Sharon Lyons shared that she recently presented brain injury talks to 5 classes for William Penn High School. A concussion is a brain injury. Her goal is to try to reach out to some of the other schools to talk about brain injuries. She talked about behaviors and didn’t gloss anything over. The big part for children and teens to know is that when it first happens their friends all come around but then they stop because they don’t want to be around anyone who is different. You have to paint a picture and let them see it.

- BIA of DE had their 27th annual conference in March. The people who chaired the conference last year don't want to do it again. Sharon is going to co-chair it with the vice-chair of the BIA of DE. Sharon asked members: What do you want to see? What do you need? Do you know anyone who would want to be involved? Sharon told everyone that any kind of input would be really, really appreciated including a theme. The conference is scheduled in March again next year. She needs key-note speakers, conference sessions, etc. Someone suggested a panel of nurses with a moderator facilitating to explain what each one of the panel members see when dealing with brain injuries. Sharon told a story about an old client who ended up doing really well. Do people know what works?
- Ann Phillips suggested a "What Now?" theme - E.g. what happens as you age with a brain injury? What do brain injury survivors need?
- Sharon stated that in Delaware she takes all of the calls that come into BIA of DE advising that there is no place for people to go. She currently has 7 or 8 people that she is looking for places to send people.
- Katie asked whether or not we ever invited any of the legislators to the conferences.
- Ron Sarg advised that if Sharon contacted school superintendents now -- she could set up an in-service training, as well as, training for the sports coaches to come to the conference.
- Sharon told members that in the past, Jane Crowley arranged for an all-day conference at A. I. DuPont Nemours on brain injuries.
- Another suggestion was to have a panel with adult survivors of TBI speaking about what they went through, and what they continue to go through. Where can they find case management? Another issue to bring up is the emergency rooms. Symptoms may match a concussion but if they take an x-ray and there is no brain bleed then according to the emergency room there is no concussion. However, concussions are diagnosed by symptoms, family impact and quality of life issues.
- Sharon requested that members send her any input, ideas, speakers and session topics by email. If you want to be involved please send Sharon an email to let her know.
- Ann Phillips stated that she is willing to be a speaker.

ANNOUNCEMENTS

- None

ADJOURNMENT

With nothing further to discuss Ron Sarg made a motion to adjourn that Sharon Lyons seconded and the voting members in attendance unanimously approved.

NEXT MEETING

The next Brain Injury Committee meeting is scheduled for
Monday, September 10 at the
Smyrna Rest Area Conference Room
at 2:00 p.m.